

Achieving Excellence in Palliative Care: Perspectives of Health Care Professionals

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Received: July 15, 2015, Accepted: August 18, 2015

ABSTRACT

Caring for individuals at the end of life in the hospital environment is a challenging proposition. Understanding the challenges to provide quality end of life care is an important first step in order to develop appropriate approaches to support and educate staff members and facilitate their capacity remaining “caring.” Four studies were undertaken at our facility to increase our understanding about the challenges health professionals experience in caring for patients at end of life and how staff members could be supported in providing care to patients and families: (1) In-depth interviews were used with cancer nurses ($n = 30$) to explore the challenges talking about death and dying with patients and families; (2) Surveys were used with nurses ($n = 27$) and radiation therapists ($n = 30$) to measure quality of work life; (3) and interprofessional focus groups were used to explore what it means “to care” (five groups held); and (4) interprofessional focus groups were held to understand

what “support strategies for staff” ought to look like (six groups held). In all cases, staff members confirmed that interactions concerning death and dying are challenging. Lack of preparation (knowledge and skill in palliative care) and lack of support from managers and colleagues are significant barriers. Key strategies staff members thought would be helpful included: (1) Ensuring all team members were communicating and following the same plan of care, (2) providing skill-based education on palliative care, and (3) facilitating “debriefing” opportunities (either one-on-one or in a group). For staff to be able to continue caring for patients at the end of life with compassion and sensitivity, they need to be adequately prepared and supported appropriately.

Key words: Caring, palliative care, quality of dying, supporting staff

Introduction

According to the World Health Organization, palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial, and spiritual.^[1] Given this definition,

the philosophy and approaches of palliative care can be of benefit throughout an individual's journey with illness, and utilized across many settings of care by all members of the health care team. The recognition that palliative care can be of value to individuals suffering from illnesses other than cancer has been growing rapidly in recent years. Palliative care is increasingly viewed as an essential component of

Access this article online

Quick Response Code:



Website: www.apjon.org

DOI:
10.4103/2347-5625.164999

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Cite this article as: Fitch MI, DasGupta T, Ford B. Achieving Excellence in Palliative Care: Perspectives of Health Care Professionals. Asia Pac J Oncol Nurs 2016;3:66-72.

comprehensive care throughout the life course and as a fundamental human right.^[2] Additionally, a person-centered holistic approach to care delivery of health and illness services is cited as a hallmark of a quality health system.^[3,4]

The need for palliative care is expected to escalate over the next several decades. The world's population continues to grow, and many countries will see increases in their older age cohorts. This means, the number of individuals who will experience illness, either chronic or life-threatening conditions, live longer with that illness, and die from that disease, is anticipated to rise significantly. The mortality from cancer alone is expected to rise from 7.4 million worldwide in 2004 to 12 million by 2030.^[5] Globally, 20 million people are in need of palliative care services at the end of life.^[6]

Given that palliative care can be delivered in most practice settings, across all stages of serious illness, and for persons of all ages and their families, nurses are in a strategic position to influence the quality of palliative care delivery throughout the trajectory of illness (ISNCC, 2015). Nurses care for patients and families in many settings and for an array of populations and their presence can play a critical role in reducing the burden of suffering for individuals who are struggling with the impact of life-limiting illness or dying from their disease. Increasingly, however, best practice in palliative care is seen as an interprofessional activity.

Despite the emerging view of palliative care, the need for, and value of, palliative care is often not recognized or acknowledged, especially in settings such as acute medical/surgical units, emergency departments, intensive care units, maternity units, nursing homes, and long-term care agencies. The expectation that palliative care would be integrated across an illness experience implies a need for knowledge and skill in palliative care by all health care professionals, regardless of practice location. Unfortunately, relatively little attention is paid in undergraduate programs for health care professionals regarding palliative and end-of-life care. In some settings, palliative care is seen as a specialty practice and not the realm of the generalist.

Additionally, there are considerable challenges currently to the provision of integrated palliative care in hospital settings. Budgetary and financial constraints, reductions in staffing numbers, shifting role expectations and scopes of practice, and emerging new models of care and interprofessional practice may all create barriers to the delivery of excellent palliative care in a hospital setting.

Background Context and Purpose of Our Work

Sunnybrook Health Science Centre is one of Canada's largest academic health science centers and it affiliated with the University of Toronto. Its mandate is to care for patients and families when "*it matters most*" with a corporate vision of "*inventing the future of health care*." Its work is built on the values of excellence, collaboration, accountability, respect, and engagement. Sunnybrook is program based, with eight programs across three campuses. The facility has 1.2 million patient visits each year and has more than 10,000 staff members and 2000 volunteers. More than 4000 health professional students have clinical experiences at the hospital annually.

Sunnybrook Health Science Centre is a quaternary academic health science center with internationally recognized cancer and trauma programs. As a result, death and dying are significant elements of the institution's overall patient and family care experience. With the approximate 30,000 admissions, 3.1% result in deaths, equating to approximately 18 deaths per week in the acute care setting. This lead to the realization that there could be significant opportunities to improve the physical, emotional, and practical needs of dying patients and their family members. We embarked on a Quality Dying Initiative with a vision of, "*dying patients, and the families receive the highest quality of care*" regardless of care setting. The goal was established as Sunnybrook will implement strategies that are patient/family, staff/clinician, and institutionally focused to achieve the highest standard in quality of care for dying patients and their family members. (See Quality Dying Initiative at <http://sunnybrook.ca> for additional information about this initiative.)

One of the aspects of the Quality Dying Initiative focused specifically on health care professionals. We thought that if we want to find ways to better support patients and families, we also need to find ways to support staff who provide this care. Understanding their perspectives about caring for individuals who were dying was identified as an important initial step in planning and organizing the strategic directions for the Quality Dying Initiative. Three studies undertaken at our facility informed our understanding about the challenges staff members experience in providing care for individuals with life-limiting illness and their families; the fourth study focused on identifying the strategies that could be used to support staff members so that they would be able to continue to provide the required level of quality care given its stressful nature. The four studies will be summarized below.

Study #1: Talking about death and dying^[7]

The purpose of this work was to explore staff nurses' perspectives about what makes it difficult to talk with cancer patients about death and dying. The aim was to understand what aspects of these conversations created difficulty for nurses and set the stage for the development of an educational program to develop their skills and comfort in this arena. In-depth interviews were held with 21 cancer nurses from inpatient ($n = 12$) and outpatient ($n = 9$) settings. The group had, on average, 19.4 years of experience caring for cancer patients (range: 1.5-25 years). A qualitative descriptive analysis was performed on the verbatim transcripts.

The overarching theme communicated by the nurses was that these conversations were always challenging whenever they were held. It did not matter how many years a nurse had been in practice, or how much exposure she had had, these types of conversations were difficult and draining. In the words of two nurses:

It is extremely emotionally draining...you have to listen with every fiber of your being...they are saying something that to them is the most important thing that they're ever going to do in their life, is die...it is so overwhelmingly important...you have to be able to listen to everything that they are saying.

When you talk about death and dying with patients, that's a very difficult, very difficult, well it is not that easy...it's kind of like walking through a minefield...it's rewarding, but very challenging.

A secondary theme was that some situations make the conversations more challenging. These situations included those where patients were not aware of or acknowledging the prognosis, when the person was very angry, when patients and families were in conflict, or when nurses did not know what the physician had told the patient. Situations are more difficult when the patient is unaware of the prognosis, the person is denying the reality of the situation, the patient and/or family members disagree with the plan of care, the person reminds you of a family member or friend, the person is close in age or circumstances to you, you have had a (recent) significant loss.

The other secondary theme was, a nurse's personal level of comfort with the topic and their experience made a significant difference in whether or not they thought they managed the conversations well. Ultimately, the readiness on the part of the individual patient was a key aspect in the situation. Two nurses spoke about the patient and family readiness:

It's really so much easier when they start the conversation. They are asking about it, about death and dying, and, you know, you know they're receptive to it and that helps.

I find, if they are aware and if the family is, if the family have been involved and are aware of the patient's wishes, like how they want to end their lives and things like that, that's better.

The nurses in this study made strong recommendations about the need for educational programming to help nurses with these difficult conversations. Most felt they had not been educated and supported in how to conduct the conversations about death and dying properly. The education programs they felt were needed were ones that were highly interactive and provided opportunity for skill development and practice having the difficult conversations, not just lectures about what to do.

Study #2: The meaning of caring to cancer care professionals^[8]

The aim of this study was to document the meaning of caring to health care providers working in a cancer center. The specific objectives were to explore similarities and differences in the perspectives of health care providers related to the experiences of caring, highlight similarities in perceptions of how health care providers convey caring, and explore organizational tensions and how these tensions impact caring within and among the professions.

Six discipline-specific focus groups were held to explore the meaning of caring within disciplines (nursing, pharmacy, social work, nutrition, medicine, and radiation therapy). Following a narrative theme analysis of these initial focus group transcripts, two interprofessional focus groups were held to present the initial findings and explore the shared perspectives of caring across disciplines.

In total 25 professionals participated in the group sessions. Twenty were female, and 22 were employed full-time. Ten had 10 years or less experience as a professional while 15 had had more than 10 years of experience.

Caring was described as an emotional experience. It refers to a means of caring for others that involves attending to the moment and stillness within interactions. It was also described as a use of self and presence during interactions; being authentic; and using smiles, eye contact, and touch; and listening.

In general, the experience of caring was described as a benefit to health care providers as individuals in one's own professional life. In the words of two participants:

"I think in one way, [caring] makes a small difference in their life one way or another and to me, that very rewarding and sort of keeps me going..."

"I think when I look back on all the years of my working, probably I have learned the most from patients and families."

However, in addition to benefits, there are also unintended consequences to caring. These unintended consequences were described as the burden experienced as a result of, or impact of, engaging in caring. The impact is felt both emotionally and professionally. In the words of participants:

You go home not so much physically exhausted...but emotionally. You find yourself mentally exhausted because you give so much all the time. And it impacts your personal life.

Whatever their needs are you are constantly taking care of them, and they are like draining your resource both mentally, as well as physically. You try to juggle the workplace, as well as what is going on in your family, so that in the end of it, sometimes a simple thing, like in my household, every time when there are peaches or apples I am the one who is eating the bruised or rotten one...so you are kind of suffering wondering, when I am going to get the fruit that is perfect?

When I came home I was physically exhausted, the suffering we have seen...I mean the tears that I think a lot of us shed there and the sad thing at the end of the day was you almost become immune to it...sometimes you do end up developing that thick skin.

I am always giving, and no one is ever giving back.

The participants talked about the need to engage in self-care measures because of the work they do. This includes taking care of emotional and physical exhaustion and being intentional about work/life balance. As examples, in their words:

I have to purposely work on detaching. Otherwise, you get that burn out where you've been stretched too far beyond.

...and I find by the end of the day you just need to look after yourself.

Working within teams was also identified as a facilitator of caring. Positive team dynamics supported caring while ineffective team relationships negatively impact caring. Teams set the tone for caring and satisfaction with team relationships is dependent upon mutual respect and good communication. As described by participants:

I mentioned within my team recently, despite us taking care of patients all day, we have to be aware of what each other needs to... just to be aware of what is going on and take care of each other too.

I think in terms of what we do well is indeed caring for patients and their families. What I would say that we don't do so well is caring for the staff afterwards...I don't know if we actually acknowledge the effect of death has on people working in health care.

A perfect day of caring...is when we are able to care for each other.

Finally, participants spoke of the importance of institutional support as a facilitator of their continued capacity to provide caring. Their perspectives have implications for supervisors and managers.

I think if you're appreciated and valued in the job you do and you feel appreciated and respected, it makes it easier to care...for others or for yourself or for the patients or for coworkers.

I want the administration to acknowledge the repeated losses, continuous losses and the impact on staff.

Study #3: Occupational stress in cancer center staff members^[9]

This study was conducted to identify the predisposing factors for occupational stress within a cancer radiation treatment department. All Rapid Response Radiotherapy Program (RRRP) team members ($n = 15$, including radiation oncologists, residents, and students), radiation therapists ($n = 130$), and ambulatory oncology nurses ($n = 80$) were asked to complete a demographic form on professional background and three standardized questionnaires (i.e., Maslach Burnout Inventory, General Health Questionnaire-12 [GHQ-12], and Professional Quality of Life Scale). Univariate general linear regression was used to determine significant demographic predictors for occupational stress, and one-way analysis of variance was used to compare stress among the three groups.

The overall response rate was 28%. Being younger ($P = 0.004$), male ($P = 0.0056$), and having less professional experience ($P = 0.008$), and being on the RRRP team was associated with a greater sense of depersonalization. Greater self-reported spirituality was predictive of higher compassion satisfaction ($P = 0.0064$). Individuals reporting no or lower spirituality experienced higher levels of burnout ($P = 0.0053$). Higher GHQ-12 scores (greater stress) were reported by participants who spend more of their time with palliative patients. Less stress was reported by staff members who spent time participating in stress relieving activities.

Specifically, 59% of the registered nurses reported low levels of professional satisfaction, 50% reported high levels of emotional exhaustion, and 86.3% reported low levels of depersonalization. Overall, greater psychological stress was reported for staff members who cared primarily for palliative care patients.

These authors concluded that working with patients with advanced illnesses can be both rewarding and stressful for healthcare professionals. When events are seen as traumatic, they can leave indelible marks on those touched by them. Health care professionals who are caring for individuals working through a “traumatic event” may react by turning off his or her own emotions or may experience feelings of helplessness, anger, guilt, or emotional distress^[10,11]

These authors emphasized the responsibilities shared by the organization and the individual staff member in fostering an environment that is supportive to staff in their continued capacity to provide quality care. The organization has an important role to continue to support health care professionals and their emotional needs, engage in dialogue about what fosters satisfaction and decreases fatigue and burn-out; equip individuals in leadership roles with the skills to recognize early signs of, and to address, the needs of health care professionals collaboratively; and introduce structures to support self-care by the staff members. The individual employee has a responsibility to be aware of the institutional support resources available, and develop and foster personal resilience through self-care.

Recommendations from this study emphasized the need to introduce strategies to help staff members reduce stress. The strategies could include developing initiatives that promote engagement in stress-relieving activities, offering stress management courses, and increasing awareness of the potential signs and causes of occupational stress.

Study #4: Perspectives on support strategies for health care professionals

This study was conducted to explore the perspectives of health care professionals about what strategies would be seen as relevant to support staff members to continue to provide quality end of life care. Six interprofessional focus groups were held with a total of 48 inpatient and outpatient staff members. The verbatim transcriptions of the sessions were subjected to a content analysis.

The participants described how it is especially challenging to care for individuals who are dying when the patient is not aware of the prognosis, the patient and the family disagree

on the plan of care, you as a health care provider do not feel comfortable with the topic or know what can be said that would be helpful, all team members are not on the “same page,” or you are feeling overwhelmed by the situation, when your caseload is heavy and there is “no time to sit and talk.” There is an emotional burden that comes with this work and it is difficult to talk with one’s own family or friends about it (“*they just don’t get it*”) or know where to turn for support.

The participants identified a number of strategies that would be relevant from their perspective for supporting staff. The strategies focused on communication with the patient, family members, and all team members; relevant educational programming; effective teamwork; debriefings as a group; availability of resource personnel; space and time for reflection; support for each other; and understanding and acknowledgement from managers about the difficulties inherent in their caring for individuals at the end-of-life. Table 1 contains direct quotes from participants illustrating their ideas for support strategies.

Conclusion

Caring for individuals at the end of life is a challenging and emotionally demanding proposition. For administrators and managers in hospital environments to find ways to meaningfully support staff is also challenging given the changes in health care delivery, budget, and staffing constraints. All are cited as increasing the stress levels for health care professions involved.

When an institution wants to see quality care for the dying, there is a need to ensure staff members can continue to provide caring interactions given the emotional toll end-of-life situations take on them personally. This requires that institutions intentionally build focused strategies to support staff members including relevant education, standing order sets or protocols, team debriefings, and meaningful strategies to acknowledge staff burden in the work. Staff members need to be adequately prepared and supported if they are to provide meaningful, and high-quality end-of-life care to patients and their family members on an on-going basis.

Acknowledgments

This article was written on the basis of a presentation given at the International Cancer Nursing Conference held in Vancouver Canada by the International Society of Nurses in Cancer Care.

Table 1: Health care professionals' perspectives about strategies to support staff members providing end-of-life care

Illustrative quotes from participants attending focus groups	
Recommended strategies to support staff members	
Patients being told about prognosis with documentation in the patient record/sharing with the whole team	When they are told...we all then are able to do our jobs better. If you know on the chart that a patient has been told, then we can all do better. Charting is so important — you know where the patient is and who said what...communicating is a key. It would help us if we were all on the same page...if the docs would talk with us and let us know what's exactly their thinking...communication between us and them...has been sort of disjointed sometimes. There are times when our medical staff don't like to acknowledge that their patient is going to die...the doctors at times will not refer early (to palliative care). Maybe when the doctors share bad news they should ask us to join in as well...we want to be on the same page...let's do it together.
Work together as a team	We need to be more integrated in our practice as an interdisciplinary team...having clear goals of care and all being on the same page...having the doctor's with the rest of us.
Time and space for reflection...debriefing	You need a quiet space. You need time...to reflect on what's happened. You need a decompression time — workshop type sessions — we did it once with painting and writing sessions at work...you could talk about all kinds of things...I found that very helpful. Have a safe place for discussions...as a team. We don't have space for those private conversations...all is so fast paced, busy, lots of people coming and going. Retreats for staff, debriefs for the team, something regular, supporting one another, talking and comforting each other...encouraging and checking in. Opportunities to debrief, for staff to sit down and talk about that patient, how they felt, what they remember...maybe understand more our own internal struggles. The idea of the closed door, a confidential team debrief, that we are able to vent and feel comfortable in the environment doing it. It's always good, after a situation that's traumatic or stressful, if the staff can debrief and share their thoughts. You can learn from each other who've been in similar situations. ...you acknowledge it. You hope that they had a peaceful death; they're not in pain anymore. And you reflect on what — on everything that you did. On what everyone did. And you personalize it — everything I did...more than a debrief. It's like a memory book, only talking. A group sessions...being able to talk, to be able to be you...you refer back to the patient, you share stories, about the fun times, about that person.
Hold meetings...to share perspectives and plan care	If we could only just meet, so you are not revisiting it...because we've cared for them as a team if we would just meet with them as a team and talk about it all. We need to meet every day, any caregivers, and the family, and have discussions about exactly what's going on so that everyone body knows. That would be ideal. I think at the beginning of the day and go over every patient who is coming in to our clinic...talk about each one...and at the end of the day, we did the exact same thing. We meet that team meetings and family meetings...everyone should just come together in the same room and hash it out...regular team meetings or family meetings with the patients we know are dying.
Provide relevant education	Ethics rounds...and quality rounds are good...teaching as a group interprofessionally...talking about how to give bad news, for example. Team meetings, team education...how to tell bad news, how to support one another, how to support patients, taking care of yourself...like self-care. I need to understand more about palliative care. It's so much different than what I learned about in school...and how can you sell something that you don't know anything about, you haven't seen?...I don't have the experience with it. Have a staff speaker series...orientation to death and dying with practical information like touching the body or not, funeral parlors, what's going to happen. Walk in the shoes of a palliative care nurse for a day, let me get and feel and know what they do...not just see it on paper. A tour of palliative care unit, spending time there would be interesting...mentorship or cross-training...for us to work together (oncology and palliative care). Giving you counseling strategies to use with your patients...you'll feel a bit more helpful...sometimes you don't know what to day and how to help them. Have something in place for students.
Resource person available	You need to learn how, you want to be caring and empathetic and you don't want to...give too much of yourself away in the process...you have to figure this is what I have control over and this is what I do not have control over. It's a fine line, a really fine line. Have some kind of resource person that is comfortable dealing with all this, that you could go to and would be empathetic and not brush it off...have it validated, the decisions you've made. You need specialized people who can spend time with patients...especially when you can't or don't feel comfortable.
Managers and leaders who understand and acknowledge the difficulties	Having a chaplain to call is really great; for patients, for families and for yourself. Have managers who understand the front line stresses...and acknowledge them. Time and resource are ways to acknowledge people...getting feedback from people about what's working and what's not. And what you're doing well. Continuity of care, seeing the same nurse is good for the patients, but it can be hard on the nurse. Assignments need to be balanced, especially the long-term palliative care, the "heavy" patients. Just the recognition that what we do, it's difficult. It's very difficult what we do...if the hospital recognizes that...I find it supportive. The manager or somebody needs to be really sort of on top of how their staff is doing and coping with a situation. Especially more stressful ones. Keep on top of the pulse of what's happening. Having time to talk as a group encouraging people to talk about it...to take the time to talk if things are upsetting them.
Support each other	Tell each other, "you did an awesome job today. You did what you could. You did the best you could do...we did an awesome job today".
Hospital policy and organization	Have automatic referral to palliative care...hospital policy should support it. It's best if there is a clear directive, say a protocol for "comfort measures only". The hospital should offer some kind of wellness option...organized yoga session three times week, say...it is a way to encourage people to take care of themselves. Meditation sessions, maybe. Or stress reduction sessions. We need to be caring for ourselves. I went to the memorial service the hospital does and I was blown away by the power of that ceremony...very powerful and it also was very useful to connect with this whole topics.

Financial support and sponsorship

Nil.

Conflicts of interest

There are no conflicts of interest.

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